2010

Forward Stride

Morgan Williams
Pacific University

Rachel Gligorea

Forward Stride

Description

Pacific University – School of Occupational Therapy students Rachel Gligorea and Morgan Williams began a new collaboration with Forward Stride – Therapeutic Riding Center, under the supervision of Occupational therapy professor, Nancy Krusen. Students' project included aiding Forward Stride in projects and further developing the effectiveness of their program. Outcomes included: Group documentation form, Marketing flyer for parents of children on the Autism spectrum, Goal in-service provided for Forward Stride instructors, Collaboration with two MOT 1 students who aided in flyer, and IRB submission and approval for research project, titled: Quality of life of parents of children with pervasive developmental disorders who are currently enrolled in a therapeutic horseback riding program. Next year's student team will complete this research project.

Disciplines

Occupational Therapy | Rehabilitation and Therapy

Forward Stride

OT 633
Innovative Practice Project
Pacific University of Oregon

May 5, 2010

Academic Advisor: Nancy Krusen Ph.D., OTR

Morgan Williams OTS
Rachel Gligorea OTS

Abstract:

Pacific University – School of Occupational Therapy students Rachel Gligorea and Morgan Williams began a new collaboration with Forward Stride – Therapeutic Riding Center, under the supervision of Occupational therapy professor, Nancy Krusen. Students' project included aiding Forward Stride in projects and further developing the effectiveness of their program. Outcomes included: Group documentation form, Marketing flyer for parents of children on the Autism spectrum, Goal in-service provided for Forward Stride instructors, Collaboration with two MOT 1 students who aided in flyer, and IRB submission and approval for research project, titled: Quality of life of parents of children with pervasive developmental disorders who are currently enrolled in a therapeutic horseback riding program. Next year's student team will complete this research project.

Introduction

The overall project of Pacific University School of Occupational Therapy students, Morgan and Rachel, aimed to address the concerns and the well-being of parents who have a child enrolled in a therapeutic riding program at Forward Stride. Quality of life is defined by the World Health Organization as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (WHOQOL, 1997). It is a multidimensional concept that cannot be simply explained with the terms health status, life style, life satisfaction, mental state or well-being. Quality of life is commonly affected in parents of children with disabilities and special needs. Having a child with a disability requires revision of roles and activities, reallocation of financial resources, and new behaviors to cope with te needs of the child, all which affect one's sense of well-being and quality of life (Soresi, Nota & Ferrari, 2007). In a 2003 National Survey of Children's Health, parents of children with disabilities reported their recent feelings about the sacrifices they have to make to care for their child, the difficulty of this, and their frustration with their child's actions and behaviors (Shieve, Blumber, Rice, Visser & Boyle, 2006). These disabilities include pervasive developmental disorders (Aspergers, High-functioning autism, other autism related disorders), cerebral palsy, mental retardation, developmental disabilities, and other physical disabilities. Areas of most significant concern regarding the parents are mental health, stress, sense of devaluation and blame, impaired physical functioning, tiredness or exhaustion (Allik, Larsson & Smedje, 2006). Addressing parental quality of life is

becoming more necessary during the course of treatment for the child and is also becoming seen as part of treating the "whole" child.

In an article published by the American Academy of Pediatrics, an Aggravation in Parenting Scale was used to measure the associations between parenting a child with autism and stress indicators (Schieve et al., 2006). Parents of children with autism were compared with parents of children with special health care needs including emotional, developmental, or behavioral problems other than autism, children with special health care needs without developmental problems, and children with special health care needs. Parents of children with autism reported higher scores on the aggravation scale and were highest if they had recent issues requiring treatment. The article also concluded the importance of considering family concerns and quality of life in developing treatment plans for children with autism due to the significance of family dynamics. Another article also examined the level of parental stress when caring for children with developmental disabilities in general and the association with child characteristics (Hastings, 2002). This article focused on Oliver's model that draws on the notion that children and parents reciprocally influence each other, thus understanding parent behavior may be crucial in understanding the behavior problems in children with developmental disabilities. The article found that the level of stress was more affected by their child's lack of ability rather than their difficult behavior. This is important for the professionals involved in order to provide the most accurate education and support for the parents when treating the child. Overall, the study proposed that reducing parental stress may have an indirect beneficial effect on the child's behavior by improving the quality of parenting behavior.

Two articles published in the Health and Quality of Life Outcomes journal looked directly at parents of children under the category of pervasive developmental disorder. The first study used the Short Form Health Survey to measure physical and mental well-being in parents, and also used the Strengths & Difficulties Questionnaire to examine child behavior characteristics. They found that mothers of children with Aspergers and High-functioning autism had poorer physical health than compared to parents of children with typical development (Allik, Larsson & Smedje, 2006). More specifically, maternal health was related to the behavioral problems of the child, such as hyperactivity and conduct. The study concluded that mothers, but not fathers, who care for children with pervasive developmental disabilities are at increased risk of impaired physical well-being. The second study also looked at parents of children with pervasive developmental disorders (PDD), but measured parental quality of life using the World Health Organization Quality of Life Questionnaire (WHOQOL-BREF) (Mugno, Ruta, D'Arrigo & Mazzone, 2007). This tool measures four domains of quality of life, including physical, psychological, social relationships, and environment (Development of the WHOQOL-BREF, 1998). In comparing parents of healthy children, the study found impairments in physical activity, social relationships, and worse overall perception of their quality of life. When comparing parents of children with mental retardation and cerebral palsy to parents of children with PDD, scores for physical, psychological, and social relationship domains were lower in the PDD category. The study concluded that parents of children with pervasive developmental disorders experience a higher burden and that those parents of high-functioning autism and Aspergers, specifically, have higher stress.

One study took the information regarding impaired maternal quality of life and looked at hardiness (the capacity for enduring or sustaining hardship) of mothers of children with autism, mental retardation or typical children, and their social support as factors to successfully decreasing stress and improving well-being (Weiss, 2002). Mothers of children with autism reported the least amount of social support and the most negative effects of stress. The study identified palliative strategies (holding philosophically comforting view of life and searching for satisfaction in other areas of life) and having a sense of control and self-efficacy as most effective for decreasing mother's level of stress. Other characteristics included the mother's sense of control, commitment to their sense of purpose and values, and sense of challenge (adventurousness and perception of events as opportunities). The study concluded that both hardiness and social support were predictive of successful adaptation. Another predictor of higher levels of strain on the parents is their ability to cope and their styles of coping, as reported by families with a child diagnosed on the Autism spectrum (Sivberg, 2002). Ineffective strategies identified include distancing and escape, unbalanced attention on the child with Autism (versus the other children in the family), viewing the child with Autism as the sole source of strain within the family, and poor problem solving. Effective strategies for parents, as suggested in the Ways of Coping Questionnaire used by the study, are self-control, social support, acceptance of responsibility, problem solving and reappraisal.

Parents of children with Attention-deficit-hyperactivity disorder also experience impaired quality of life (Xiang, Luk & Lai, 2009). Parents reported low scores in the domains of physical, psychological, social, and environment and was

related to the severity of emotional and hyperactivity/inattention symptoms. The study also identified the parents' educational level, income and medical conditions as factors contributing to their quality of life.

Another contributing factor to one's quality of life is the ability to engage in the occupations, or activities, which are desired and required to do. This perspective is central to the practice of occupational therapy, as laid out by the Occupational Therapy: Practice and Domain document (OTPF, 2002). Fingerhut's study on the impact of caring for children with special needs on the parents' ability to engage in occupations contributes evidence towards the importance of examining some of the parent's issues during the course of treatment of the child. An instrument was developed based on the seven domains of occupational therapy (activities of daily living, instrumental activities of daily living, work, social participation, education, play, and leisure), titled: Life Participation of Parents (LPP). Overall the parents of children with special needs recognized a decreased ability to engage in the activities that fit under the above categories. This could be a further area for Forward Stride to develop in their programming.

Process:

Innovative Practice Projects, developed and completed by third-year students in preparation for graduation, often forge new relationships with programs or continue with existing projects initiated by former students. Nancy Krusen, an advisor for students completing capstone projects, has had previous experience in the field of hippotherapy; it was a natural decision to develop a relationship with Forward Stride. Forward Stride is a

non-profit organization that provides therapeutic riding programs for individuals with and without disabilities. The program is one of the largest in the state and provides services to individuals across the lifespan with various degrees of disabilities. To identify areas of assistance from the Pacific students, a meeting took place to define terms, express mission statements from each party, narrow down areas of interest, declare intentions by Pacific University students and build rapport between the two parties. During the meeting, individuals at Forward Stride express a need for building a foundation of data to measure the effectiveness of their program. They shared a desire for class instructors to have a enhanced understanding of goal writing and documentation to measure the progress of individual clients. A need for current research information for parents and caregivers stating the effectiveness of this type of intervention was identified. Needs that were identified but unable to be met by the current Pacific Students will be addressed later in the paper.

Collaboration began with direct observation of hippotherapy and sport riding sessions. During observation, Morgan and Rachel had the opportunity to discuss the program with parents whose children were in the sport-riding program. Of the parents that were spoken to, each of their children had a diagnosis of autism and had been in the program for approximately a year. The parents spoke about gains both of their children had demonstrated and out of all the therapy and services provided for the symptoms of autism, that hippotherapy and sport-riding classes had been most effective. Stated changes in behavior include an increase in spontaneous social interactions, increased communication, and a decrease in negative behaviors. During the conversation, the students were given an inside look at the process and reactions from some parents of receiving a diagnosis of autism for their child. They openly suggested tactics to

providing possibly damaging information and even therapy during sensitive moments of physical and emotional drain.

An objective provided by the organization was for the students to partake in volunteer training to learn more about the tenets of Forward Stride and gain an in-depth understanding of how the organization provides services to it's clients. Volunteer training was approximately three hours and provided information on the organization as a whole, how to prepare a horse for a riding session, how to operate within the facility and safety precautions before, during, and after a session.

Once rapport was established, communication and networking increased between the two parties regarding the proposed research project. To initiate the research proposal, Morgan and Rachel completed the NIH ethics training online required by the Institutional Review Board (IRB). This was paramount in appreciating the ethics and consideration for research participants in completing a research project. Before the proposal was fulfilled, evaluations to collect data were chose based on the desired outcomes and realistic expectation of overall completion by participants. The Strengths and Difficulties Questionnaire (See Appendix A: Strengths and Difficulties) and the World Health Organization Quality of Life-BREF (WHOQOL-BREF) questionnaire (See Appendix B: WHOQOL-BREF) were chosen as evaluation methods. A request for permission to use the WHOQOL-BREF for data collection was required from the World Health Organization (WHO) to comply with copyright laws (See Appendix C: Permissions Letter to use WHOQOL-BREF). In addition to the NIH training and formal documents allowing us to use the WHOQOL-BREF, the IRB also required a permissions letter from Forward Stride, the organization in which we were working to illustrate their cooperation with Pacific University and the proposed research project (See Appendix D: Permissions Letter: Forward Stride). An initial proposal was developed by the students along with

the necessary documents to support the proposal. The students made contact with the Institutional Review Board (IRB) and began the process of applying to construct a research project titled: *Quality of life of parents of children with pervasive developmental disorders who are currently enrolled in a therapeutic horseback-riding program.* (See Appendix E: IRB Proposal)

Research Methods:

Participants will be recruited by asking parents new to Forward Stride to enroll in a study examining the impact of therapeutic riding on their lives. Researchers will review with participants the informed Consent to Participate, evaluation forms and ability to withdraw from the study. Participants will complete an initial WHOQOL, SDQ and Appendix IV at the time their riders begin the therapeutic riding program. Six months following the start of the therapeutic riding program, participants will be asked to complete a second WHOQOL and SDQ. Participants will be finished with participation at that time. Researchers will use a modified baselines method of comparing quality of life. The study will take place at the Forward Stride, 18218 SW Horse Tale Dr., Beaverton, OR 97007. The study will begin May 20, 2010 and will take place for 12 months. Nancy Krusen and two future Pacific University Occupational Therapy Students will complete the gathering and interpretation of the data by May 2011. When future students are added to this research project, the students will provide the appropriate training certificates in order to complete the study.

The proposal along with necessary appendix items, were delivered in hard copy format along with an electronic copy to the IRB for review. The full review of the proposal began soon after and comments/suggestions to adequately describe consent and methods were returned to Nancy and passed along to the students. The proposal was updated in reference to the suggestions provided and sent again for a second review. A

second batch of comments was presented to clarify language used to describe methods of confidentiality for all participants along with issues related to direct benefits. The IRB also requested that all proposals be sent through the advisor, which had not been done previously. Once the proposal is cleared by the IRB, a research packet will be distributed to Forward Stride for each willing participant to complete once upon initial evaluation and then for a second time at the six-month interval.

As a new addition to the Innovative Practice Projects, mentor-mentee partnerships were developed between MOT3 and MOT1 students. The MOT1 students are to become involved in the capstone projects by means of contributing to the outcome or process of the project. Two students were assigned to Morgan and Rachel who were initially interested in becoming involved in the Forward Stride organization. An identified need addressed by Forward Stride was to have a flyer or brochure demonstrating an evidence-based platform that was to be distributed to parents and caregivers of individuals considering enrolling in the program. The flyer needed to be understood by the audience, be unique and pleasing to the eye, and provide information on research findings in the field of therapeutic horseback riding. After several meetings and rough drafts, the MOT 1 students presented a flyer that met the criteria.

One of the identified areas of mutual benefit was from a desire from the instructors to learn how to write measurable, realistic, and meaningful goals. The instructors acknowledged a lack of skills for accurately pinpointing the "just right challenge" in their goal writing to further along the development of their riders. A main concern was developing goals that were both measurable and realistic. It was decided that the students would provide a goal writing in-services during an instructors meeting to provide information relevant to goal writing strategies. In addition to the presentation, a goal sheet was developed to accurately capture the levels of progress using the goal

writing techniques that were addressed (See Appendix F: Goal Documentation Form). The goal sheet was presented along with the in-service to provide adequate direction in how to utilize the form and improve overall documentation, especially for group classes. Tables were made to track each child's goals in each session. A rating system composed of 5 levels was also developed and described to increase ease and efficiency in using the form. This was well received by Forward Stride group therapy staff.

The rating system for the goal documentation sheet is as follows:

1= skill just emerging
2=max assistance required, can perform about 10-20% of the time
3=mod assistance required, can perform about 50% of the time
4=min assist required, can perform about 75% of the time
5=skill mastered, can perform skill independently about 95-100% of the time

The in-service was scheduled for April 5, 2010 at 7:00pm as was set for 30 minutes. Two hours before the in-services was to be held, a windstorm swept the valley and caused major power-outages and fallen trees, making the facility unsafe. The in-service was rescheduled to May 10, 2010 at 7:00pm, again for 30 minutes during an instructor meeting. After the in-service, the instructors were asked to fill out an evaluation measuring the perceived effectiveness of the information provided (See Appendix G: Goal In-service Evaluation Form).

Future Capstone Projects:

- A focus group ran by Pacific University students for parents and caregivers of individuals enrolled in either hippotherapy or sport riding classes to assess ways to increase communication between family members and instructors/therapists. Focus groups could also benefit Forward Stride

- More research could be done measuring specific functional outcomes related to hippotherapy and sport riding classes.

- Utilizing the results of the current research project (*Quality of life of parents of children with pervasive developmental disorders who are currently enrolled in a therapeutic horseback-riding program*) could lead to developing a more family-centered approach for Forward Stride, helping the parents of the enrolled children engage in occupations or activities that would support a better quality of life.

- A new program that Forward Stride has recently begun to develop helps wounded veterans from the Iraq War regain independence and leisure activities through sport riding classes. The program is called Wounded Warriors and plans to begin in the next month or two.

- Along with the Boy Scouts of America, Forward Stride has recently developed a sensory trail on their property. Although the trail is equip with wooden kiosks and posts, further development is needed to provide an overall sensory experience for each individual encountering it.

- Fundraising and volunteer help is what makes Forward Stride the amazing and powerful organization that it is. There will always be a need for more funds and recruitment power at Forward Stride.

Conclusion:

The partnership developed by the individuals at Forward Stride, head advisor Nancy Krusen and the students and Pacific University have only begun to tap into the

potential generated between the two organizations. Although Forward Stride is a successful non-profit organization, they continue to struggle with financial concerns and providing evidence of their overall effectiveness. The organization has been a major support in their community, helping individuals with disabilities by providing alternative therapy that can address a variety of diagnoses and functional goals. The program not only provides an innovative therapeutic option, but leisure and extra-curricular activities for children and adults. This effect generally leads into the phenomenon of a normalizing effect that may be produced when therapy is provided outside of the clinic and the modality is a horse and saddle. As the relationship develops, trust and communication will continue to grow, building a foundation of collaboration and support. With any new relationship, trust and understanding of intentions and boundaries was an obstacle that was slowly broken down with continued interactions and open communication. As the partnership continues, there are several opportunities for mutual benefit from each organization as students learn to collaborate with an organization, providing services in the role of a consultant, researcher and advocate.

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Appendix A:

Strengths and Difficulties Questionnaire

P 4-10

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain. Please give your answers on the basis of your child's behavior over the last six months.

Your child's name ..... Male/Female

Date of birth.....

	Not True	Somewhat True	Certainly True
Considerate of other people's feelings	☐	☐	☐
Restless, overactive, cannot stay still for long	☐	☐	☐
Often complains of headaches, stomach-aches or sickness	☐	☐	☐
Shares readily with other children, for example toys, treats, pencils	☐	☐	☐
Often loses temper	☐	☐	☐
Rather solitary, prefers to play alone	☐	☐	☐
Generally well behaved, usually does what adults request	☐	☐	☐
Many worries or often seems worried	☐	☐	☐
Helpful if someone is hurt, upset or feeling ill	☐	☐	☐
Constantly fidgeting or squirming	☐	☐	☐
Has at least one good friend	☐	☐	☐
Often fights with other children or bullies them	☐	☐	☐
Often unhappy, depressed or tearful	☐	☐	☐
Generally liked by other children	☐	☐	☐
Easily distracted, concentration wanders	☐	☐	☐
Nervous or clingy in new situations, easily loses confidence	☐	☐	☐
Kind to younger children	☐	☐	☐
Often lies or cheats	☐	☐	☐
Picked on or bullied by other children	☐	☐	☐
Often offers to help others (parents, teachers, other children)	☐	☐	☐
Thinks things out before acting	☐	☐	☐
Steals from home, school or elsewhere	☐	☐	☐
Gets along better with adults than with other children	☐	☐	☐
Many fears, easily scared	☐	☐	☐
Good attention span, sees chores or homework through to the end	☐	☐	☐

Do you have any other comments or concerns?

Overall, do you think that your child has difficulties in one or more of the following areas: emotions, concentration, behavior or being able to get on with other people?

No	Yes- minor difficulties	Yes- definite difficulties	Yes- severe difficulties
☐	☐	☐	☐

If you have answered "Yes", please answer the following questions about these difficulties:

- How long have these difficulties been present?

Less than a month	1-5 months	6-12 months	Over a year
☐	☐	☐	☐

- Do the difficulties upset or distress your child?

Not at all	Only a little	Quite a lot	A great deal
☐	☐	☐	☐

- Do the difficulties interfere with your child's everyday life in the following areas?

	Not at all	Only a little	Quite a lot	A great deal
HOME LIFE	☐	☐	☐	☐
FRIENDSHIPS	☐	☐	☐	☐
CLASSROOM LEARNING	☐	☐	☐	☐
LEISURE ACTIVITIES	☐	☐	☐	☐

- Do the difficulties put a burden on you or the family as a whole?

Not at all	Only a little	Quite a lot	A great deal
☐	☐	☐	☐

Signature ..... Date .....

Mother/Father/Other (please specify:)

Thank you very much for your help

Appendix B:

WHOQOL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. **Please choose the answer that appears most appropriate.** If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last four weeks.**

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
4.	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15.	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you with yourself?	1	2	3	4	5

20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24.	How satisfied are you with your access to health services?	1	2	3	4	5
25.	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1

Do you have any comments about the assessment?

_____

_____

[The following table should be completed after the interview is finished]

		Equations for computing domain scores	Raw score	Transformed scores*	
				4-20	0-100
27.	**Domain 1**	(6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18 ☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐	a. =	b:	c:
28.	**Domain 2**	Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26) ☐ + ☐ + ☐ + ☐ + ☐ + ☐	a. =	b:	c:
29.	**Domain 3**	Q20 + Q21 + Q22 ☐ + ☐ + ☐	a. =	b:	c:
30.	**Domain 4**	Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25 ☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐	a. =	b:	c:

* See Procedures Manual, pages 13-15

Appendix C:

University of Washington
School of Public Health
and Community Medicine

USER AGREEMENT

Permissions for use of the World Health Organization Quality of Life (WHOQOL-BREF) Instrument

Date: March 15, 2010

CONTACT INFORMATION

Name: **Rachel Gligorea**

Agency/University/Company: **Forward Stride, and Pacific Universirt**

Full Address: **Forward Stride, PO Box 19805, Portland OR 97208**

Country: **USA**

Phone: **503-575-6710** Fax: **503-682-9012**

E-mail: **boam4974@pacificu.edu**

Study Title: **Quality of Life of parents of children with pervasive developmental disorders who are currently enrolled in a therapeutic horseback riding program.**

The Seattle Quality of Life Group gives permissions to the contact listed above for use of the WHOQOL-BREF instrument in the research study "Quality of Life of parents of children with pervasive developmental disorders who are currently enrolled in a therapeutic horseback riding program", having received a completed order form and an agreement to the terms and conditions listed within this document.

Signature: _____ Date: 03/15/2010

Appendix D:

FORWARD STRIDE

February 15, 2010

Forward Stride hereby gives permission to Rachel Gligorea and Morgan Williams from Pacific University's School of Occupational Therapy to conduct the following Innovative Practice Project on our premises: "The Overall Quality of Life of Parents and Caretakers of Children with Autism who are Currently Enrolled in a Therapeutic Horseback Riding Program and the Perceived Effectiveness of the Program."

Rachel Gligorea and Morgan Williams will be allowed access to patient and care-provider information – under the supervision of Forward Stride staff – in order to collect data regarding the effectiveness of Forward Stride's Hippotherapy and Therapeutic Sport-Riding programs, especially as these programs impact clients with autism. **Confidentiality of patient records will be maintained at all times.** While Forward Stride grants initial access to parents of hippotherapy clients, their participation in research surveys will be voluntary, and researchers will respect parents' decisions in this regard.

Rachel Gligorea and Morgan Williams will be required to sign Forward Stride's volunteer release forms and to undergo Forward Stride's standard volunteer training before beginning their work.

Bill Mitchell
Acting Executive Director

Independence ★ Confidence ★ Smiles
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Appendix E:

Proposal to Conduct Research Involving Human Subjects:
Adult, Non-Protected Population

Instructions – Read this information carefully and follow it completely

1. Only use this form if your intended participants are fully autonomous adults (i.e., aged 18-years and above, who are not of a federally protected population).

2. Answer every question that follows completely and clearly. Do not use discipline-specific jargon. Assume your audience is intelligent, but I to this subject area. Type your answers to the questions that follow directly into this form in the space indicated. Delete the text indicating where your information is to be inserted and make sure the font color is set to black.

3. Include the following Appendices; in as much as is possible, please make the submission one file rather than a series of separate documents:

- ☐ All materials used for data collection; note that it is not a copyright violation to copy proprietary materials for IRB purposes; if the materials in use are complex and standard for your field (e.g., the Minnesota Multiphasic Personality Inventory, the Wechsler Adult Intelligence Scale) you may elect to not include the materials. Please check with your college/school's IRB representative for help in making this determination.

- ☐ Completed Informed Consent Form or elaborate discussion of alternate methods of consent, should written consent be unadvisable. Consent forms are to be written in the 2nd person (e.g., "You are invited to participate in a study on … . Your records will be kept private…) and at an 8th grade reading level.

- ☐ Should the research take place off-campus, include a letter of permission from the sponsoring agency or campus who is granting you access to potential research participants.

- ☐ All recruitment materials: flyers, email text, and the like

- ☐ Other release forms if needed, such as Video/Photographic or HIPAA forms

- ☐ Completion certificates of on-line NIH ethics training for those Pis or research associates who have not yet turned a form in to the IRB Office (one only need turn a certificate in once to the IRB Office)

4. If your intended sample does not speak English as their first language, all materials, release forms, and consent forms must be translated appropriately. It is the principal researcher's responsibility to procure and pay for translation services. Copies of the English and translated materials must be included in your submission.

5. Print a copy of the complete document and relevant appendices. Have all listed parties sign by their names.

6. Submit the hard copy to the IRB Office, attention Karla Staihar, Office of Research.

7. Submit an electronic copy to the IRB Office: irb@pacificu.edu

8. Your file will not be processed until all elements are received by IRB Office Personnel

9. Once your submission is received a number will be assigned to your case. Please use this number in all future dealings with the IRB regarding this submission. Note that the IRB office will do all communication only with the PI or the faculty advisor should the PI be a student.

10. Once your project is approved, please note the following: (a) Once your project is completed you must submit a final report; (b) If your research extends beyond the approved study dates you must complete a continuing review form; (c) The IRB retains the right to request continuing review of studies presenting more than minimal risk.

1. What is the title of this study?

Quality of life of parents of children with pervasive developmental disorders who are currently enrolled in a therapeutic horseback riding program.

2. Who are the research personnel and what is their contact information? Note that all student projects must be directed by a faculty advisor, who serves as the liaison with IRB personnel. Modify the columns in the table below to fit the number of personnel involved in the study; label each person in the column heading as indicated (e.g., Principal Investigator, Faculty Advisor, Research Assistant). Dissertation readers need not be named.

	Faculty Advisor	Occupational Therapy Student	Occupational Therapy Student
Name	Nancy E. Krusen	Rachel L. Gligorea	Morgan R. Williams
Institution	Pacific University	Pacific University	Pacific University
Program	Occupational Therapy	Occupational Therapy	Occupational Therapy
Email	nekrusen@pacificu.edu	boam4974@pacificu.edu	will0935@pacificu.edu
Telephone	503.352.7349	503.575.6710	503.819.5923
Signature	Nancy E. Krusen	Rachel L. Gligorea	Morgan R. Williams

3. What is the purpose of this study? Include information relevant to allow the IRB to determine the scientific merit of the proposed research, including study hypotheses.

The purpose of the study is to examine the quality of life of parents (or other legal guardians) of children who are currently enrolled in a therapeutic horseback riding program provided at Forward Stride. Assessment of parent quality of life will help determine the impact of the program. Additional information may emerge from parent report regarding changes in rider behavior. The study will contribute to evidence-based practice by examination of horseback riding as a therapeutic activity.

4. Please describe relevant characteristics of your intended sample (e.g., those individuals from whom you intend to collect personal information)**.**

a. Intended Sample Size: 15-30

b. Relevant Demographics of Sample (e.g., age range, sex/gender, ethnic/minority representation)

Study participant must be 18 years old or older and act as the primary caregiver; can be male or female and of any ethnicity

c. Exclusionary Criteria: Study will exclude adults (18+) who are neither parent nor legal guardian of a rider. Study will exclude adults without English fluency.

5. What materials, measures, and/or apparatus do you plan to use? Name and explain each element making note of what its purpose is; refer to appropriate appendices for sample items or images as needed.

Appendix I. The World Health Organization Quality of Life (WHOQOL) – BREF- is an international cross-culturally quality of life assessment instrument comprising 26 items, measuring the following broad domains: physical health, psychological health, social relationships, and environment. The WHOQOL will be given to parents as their children begin a therapeutic riding program and 6 months after beginning the program. The purpose is to examine correlations between parent quality of life and rider participation in the Program. (Tool is not only for autism.). Permission to use this questionnaire is in Appendix Ia (friendly correction).
Appendix II. The Strengths and Difficulties Questionnaire (SDQ)- is a brief behavioral screening questionnaire for 3-16 year olds that is completed by parents or caregivers. It exists in several versions, each version includes between one and three of the following components: emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, and pro-social behavior.
Appendix III. A cover letter will be attached in the front of the questionnaire packet to explain the details and purpose of the study.
Appendix IV. After the cover letter will be an open-ended questionnaire developed by the investigators to gain information on demographics of new participants.
Appendix V. (friendly suggestion) A permission letter from the University of Washington, School of Public Health and Community Medicine giving Pacific University, Rachel Gligorea, and Forward Stride permission to use the WHOQOL- BREF for this research project.

6. What is the study procedure? Denote study design if necessary. List in a step-by-step fashion how the study will unfold. In reading this, the IRB reviewers should be able to imagine exactly what it would be like to be a participant in every condition of the proposed research.

Participants will be recruited by asking parents new to Forward Stride to enroll in a study examining the impact of therapeutic riding on their lives. Researchers will review with participants the informed Consent to Participate, evaluation forms and ability to withdraw from the study. Participants will complete an initial WHOQOL, SDQ and Appendix IV at the time their riders begin the therapeutic riding program. Six months following the start of the therapeutic riding program, participants will be asked to complete a second WHOQOL and SDQ. Participants will be finished with participation at that time. Researchers will use a modified baselines method of comparing quality of life. The study will take place at the Forward Stride, 18218 SW Horse Tale Dr., Beaverton, OR 97007. The study will begin May 20, 2010 and will take place for 12 months. Nancy Krusen and two future Pacific University Occupational Therapy Students will complete the gathering and interpretation of the data by

May 2011. When future students are added to this research project, the students will provide the appropriate training certificates in order to complete the study.

7. Where will the study take place?

The study will take place at the Forward Stride facility, 18218 SW Horse Tale Dr., Beaverton, OR 97007.

8. Note whether this research is supported by grant monies. If yes, list the granting source.

No grant monies are necessary to complete research project.

9. What is the anticipated time frame of the study?

April 1, 2011 (Run study for 12 mos. Next group 2011 will pick up and evaluate data.)

10. What risk does this study pose to participants? Risk can be physical, social, emotional, or economic. Disclose the possible risks here.

The study poses minimal risks. Filling out the questionnaires may prompt negative emotional feelings. Enrollment is voluntary and with minimal physical, social, emotional, or economic risk to the participants. Participants have the opportunity withdraw from the study at any time without consequences to a riders' participation in the Program. Participants are guardians or parents of children will special needs with established community support systems. If they experience any emotional or psychological concerns during involvement in the study, they will be referred to these existing medical, educational, psychosocial or spiritual supports. Breech of confidentiality is also possible, potentially causing emotional distress.

11. How will each risk named above be minimized?

Participants will be given an informed consent sheet with a verbal explanation of what purpose and outcomes of the study including a clear statement of the option to leave the study. Participants will be offered further explanation of the two questionnaires and a chance to review each before participating. All documents involved in this Program will be kept password protected and hard documents locked in a filing cabinet to decrease risk of breech.

12. Adverse Event Reporting. Should an unexpected and adverse reaction occur, explain what you will do.

In the case of a minor adverse reaction reasonably attributable to participation in the study (e.g.), the investigators will notify the IRB by the next normal working day. In the case of

more serious adverse events that occur during or for a reasonable period following the study (e.g.), the investigators will notify the IRB within 24 hours.

13. Does participation in this study present participants with direct benefit? That is, will participants gain an advantage by participating, that they would not experience otherwise?

There are no direct benefits to participating in the study by participants filling out the forms and questionnaires. Participants in the study may indirectly benefit through participation in this Program by gaining insight into the effect of therapeutic riding for their children, having a chance to evaluate their situation and make life-altering changes for themselves and/or child. Indirect benefits also include improving the quality of equine assisted activities provided by the Forward Stride staff and identifying current issues the participant's child is experiencing that the Forward Stride staff may not be aware of thus improving the accuracy of goals set for the child.

14. Will participants get paid or be otherwise compensated for their participation?

Participants will not be paid or compensated for participation.

15. How will you protect the privacy of your participants? Explain what steps you will take to protect the personal information your participants provide you with. Make it clear whether the results will be kept in a confidential or an anonymous manner, keeping in mind that data cannot be both. A promise of confidentiality means that though names can be associated with data, steps will be taken to minimize the possibility that someone other than the PI could do so. A promise of anonymity means that no one, not even the PI, can associate names with data.

Data collected and reported will be kept confidential, only the researchers and employees at Forward Stride will have access to the personal information related to questionnaires. Names, birth dates, and parent signatures provided on each questionnaire will be kept confidential by the above personnel (Nancy Krusen, Rachel Gligorea, and Morgan Williams), as well as Forward Stride staff. These are the only individuals that will access to the data. Electronic data will be password protected and hard documents retained in a locked filing cabinet as confidential material for up to 7 years following the study by Nancy Krusen. At that time research documents will be destroyed.

16. Elaboration of the informed consent process. Explain whether the informed consent process will occur explicitly (i.e., via reading and signing the form that follows), implicitly (i.e., informed consent will not be collected), or post-study (i.e., done after the fact to avoid contamination of deception procedures). If informed consent is not done explicitly pre-study, denote the process you will follow to ensure that no participants take part in your study naively or unwillingly. If informed consent is done post-study, explain debriefing procedures and rational for the choice. Discuss how participants in the latter two possibilities would be able to withdraw their data.

The informed consent process will occur explicitly by reading and signing the informed consent form prior to the completion of the questionnaire or survey.

Appendix E:

Informed Consent Form

1. Study Title

The Overall Quality of Life of Parents and Caretakers of Children with Autism who are Currently Enrolled in a Therapeutic Horseback Riding Program and the Perceived Effectiveness of the Program

2. Study Personnel

	Factory Advisor	Occupational Therapy Student	Occupational Therapy Student
Name	Nancy E. Krusen	Rachel L. Gligorea	Morgan R. Williams
Institution	Pacific University	Pacific University	Pacific University
Program	Occupational Therapy	Occupational Therapy	Occupational Therapy
Email	nekrusen@pacificu.edu	boam4974@pacificu.edu	will0935@pacificu.edu
Telephone	503.352.7349	503.575.6710	503.819.5923

3. Study Location and Dates

The study will take place at the Forward Stride, 18218 SW Horse Tale Dr., Beaverton, OR 97007. The study will begin April 1, 2010 and will take place for 12 months. Nancy Krusen and two future Pacific University Occupational Therapy Students will complete the gathering and interpretation of the data by May 2011. When future students are added to this research project, the students will provide the appropriate training certificates to the IRB in order to complete the study.

4. Study Invitation and Purpose

You are invited to participate in a study that will take place at Forward Stride. The purpose of the study is to examine the quality of life of parents (or other legal guardians) of children who are currently enrolled in a therapeutic horseback riding program provided at Forward Stride. Assessment of parent quality of life helps to determine the impact of the program. Additional information may emerge from parent report regarding changes in rider behavior. The study contributes to evidence-based practice by examination of horseback riding as a therapeutic activity.

5. Study Materials and Procedures

Participants are recruited by asking parents new to Forward Stride to enroll in a study examining the impact of therapeutic riding on their lives. Researchers will review with participants the informed Consent to Participate, evaluation forms and ability to withdraw from the study. As a participant in this study, you will be asked to fill out two questionnaires: The World Health Organization's Quality of Life (WHOQOL-BREF) and the Strengths and Difficulties Questionnaire (SDQ) at the beginning of the participation and then again six months later. The WHOQOL is a quality of life assessment instrument comprising 26 items, measuring the following broad domains: physical health, psychological health, social relationships, and environment. The SDQ is a brief behavioral screening questionnaire for 3-16 year olds that is completed by parents or caregivers. It includes between one and three of the following components: emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, and pro-social behavior. Completion of both questionnaires will take approximately 30 minutes, taking 1 hour total of your time during the entire participation in this Program. Participants will be finished with participation after the second battery of questionnaires is completed. Researchers will compare scores between the first and second WHOQOL and SDQ.

As a participant, you will be notified that you can choose to complete the evaluations and can stop at anytime throughout the process and it will not affect the child's participation in the therapeutic riding program. Analysis of data, along with thorough literature review will provide Forward Stride along with students and faculty of Pacific University with the results of the study during a final presentation of the overall components of the project.

6. Participant Characteristics and Exclusionary Criteria

Study participant must be 18 years old or older and act as the primary caregiver; can be male or female and of any ethnicity.
Study will exclude adults (18+) who are neither parent nor legal guardian of a rider. Study will exclude adults without English fluency.

7. Anticipated Risks and Steps Taken to Avoid Them

The study poses minimal risks. Filling out the questionnaires may prompt negative emotional feelings. Full verbal explanation regarding process of participation will be explained and further information on the two questionnaires will be available to review before participating. Breech of confidentiality is also a possible risk, potentially causing emotional distress. All documents involved in this Program will be kept password protected and hard documents locked in a filing cabinet to decrease risk of breech. Enrollment is voluntary and with minimal physical, social, emotional, or economic risk to the participants. As a participant, you have the opportunity to withdraw from the study at any time without consequences to a riders' participation in the Program. Enrollment is voluntary and with minimal physical, social, emotional, or economic risk to the participants. If you experience any emotional or psychological concerns arising during participation in the study, please contact a member of your current medical, educational, psychosocial or spiritual support team. All participants involved are given an informed consent sheet with a verbal explanation of what purpose and outcomes of the study including a clear statement of the option to leave the study.

8. Anticipated Direct Benefits to Participants

There are no direct benefits to participating in this study. Overall indirect benefits may include improving the quality of equine assisted activities provided by the Forward Stride staff and identifying current issues the participant's child is experiencing that the Forward Stride staff may not be aware of thus improving the accuracy of goals set for the child.

9. Clinical Alternatives (i.e., alternative to the proposed procedure) **that may be advantageous to participants**

Not applicable

10. Participant Payment

Participants will not be paid or compensated for participation.

11. Medical Care and Compensation In the Event of Accidental Injury

During your participation in this project it is important to understand that you are not a Pacific University clinic patient or client, nor will you be receiving complete occupational therapy as a result of your participation in this study. If you are injured during your participation in this study and it is not due to negligence by Pacific University, the researchers, or any organization associated with the research, you should not expect to receive compensation or medical care from Pacific University, the researchers, or any organization associated with the study.

12. Adverse Event Reporting Plan

In the case of a minor adverse reaction reasonably attributable to participation in the study (e.g.), the investigators will notify the IRB by the next normal working day. In the case of more serious adverse events that occur during or for a reasonable period following the study (e.g.), the investigators will notify the IRB within 24 hours.

13. Promise of Privacy

Your privacy is important to us. Confidentiality of information is a priority during this study and all information will be kept in a locked filing cabinet for up to 7 years following the study. At that time research documents will be destroyed. If we present or publish the research finding, no one will be able to identify you or your child. The results will be presented as group results in a statistical format. Names, birth dates, and parent signatures provided on each questionnaire will be kept confidential by the above personnel (Nancy Krusen, Rachel Gligorea, and Morgan Williams), as well as Forward Stride staff. These are the only individuals that will access to the data. Electronic data will be password protected and hard documents retained in a locked filing cabinet as confidential material for up to 7 years following the study by Nancy Krusen. At that time research documents will be destroyed.

14. Voluntary Nature of the Study

Your decision whether or not to participate will not affect your current or future relations with Pacific University or Forward Stride. If you decide to participate, you are free to not answer any question or withdraw at any time without prejudice or negative consequences.

15. Contacts and Questions

The researcher(s) will be happy to answer any questions you may have at any time during the course of the study. Complete contact information for the researchers is noted on the first page of this form. If the study in question is a student project, please contact the faculty advisor. If you are not satisfied with the answers you receive, please call Pacific University's Institutional Review Board, at (503) 352 – 1478 to discuss your questions or concerns further. All concerns and questions will be kept in confidence.

16. Statement of Consent

I have read and understand the above. All my questions have been answered. I am 18 years of age or over and agree to participate in the study. I have been offered a copy of this form to keep for my records.

_____

Participant's Signature
Date

_____

Investigator's Signature
Date

17. Participant contact information

This contact information is required in case any issues arise with the study and participants need to be notified and/or to provide participants with the results of the study if they wish.

Would you like to have a summary of the results after the study is completed? ___Yes ____No

Participant's name: (Please Print) _____

Street address: _____

Telephone: _____

Email: _____

Appendix F: Group Documentation Form

Name: **DOB:** **Dx:**

Goals	Date											
1.												
2.												
3.												
4.												
5.												
Therapist initials:												

Name: **DOB:** **Dx:**

Goals	Date											
1.												
2.												
3.												
4.												
5.												
Therapist initials:												

Name: **DOB:** **Dx:**

Goals	Date											
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2.												
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Therapist initials:												

Name: **DOB:** **Dx:**

Goals	Date											
1.												
2.												
3.												
4.												
5.												
Therapist initials:												

Rank
1= skill just emerging
2=max assistance required, can perform about 10-20% of the time
3=mod assistance required, can perform about 50% of the time
4=min assist required, can perform about 75% of the time
5=skill mastered, can perform skill independently about 95-100% of the time

Appendix G: In-service Evaluation Form

Evaluation Form for Goal Writing In-service:

We are interested in your assessment of the effectiveness of the in-service provided April 5, 2010. For each statement, please indicate if you agree or disagree using a rating scale form 1 to 5. A rating of "**1**" indicates that you **strongly disagree** with the statement while a rating of "**5**" indicates that you **strongly agree** with the statement. A score of "**3**" indicates you **neither agree nor disagree** or have no opinion.

Elements of the in-service	**Circle your response** Disagree ----------Agree				
The in-service offered sufficient opportunities for participant questions and discussion.	**1**	**2**	**3**	**4**	**5**
The practice handout provided during the in-service was beneficial to my learning.	**1**	**2**	**3**	**4**	**5**
The topic was clearly defined and objectives clearly stated.	**1**	**2**	**3**	**4**	**5**
I was generally satisfied with most of the aspects of the in-service.	**1**	**2**	**3**	**4**	**5**
The information provided during the in-service is applicable to my work at Forward Stride.	**1**	**2**	**3**	**4**	**5**
The presentation provided sufficient information regarding the process of goal writing.	**1**	**2**	**3**	**4**	**5**
The presenters were well prepared and shared the information in a complete and clear manner.	**1**	**2**	**3**	**4**	**5**

Comments: